

## Who is infected with HIV but does not yet know? Detailed Data Tables and Technical Notes

### Technical Notes:

The U.S. Centers for Disease Control and Prevention (CDC) has recently estimated that about one-quarter of HIV infected persons nationwide do not know they are infected<sup>1</sup> (previous editions of the Epidemiologic Profile estimated that about one-third of HIV-infected persons either did not know they were infected or were not in care in Massachusetts). People unaware of their status do not access HIV-related care and treatment, and, therefore, are unable to experience the benefits of these services, including improved health, better quality of life and longer survival. Additionally, they lack the opportunity to be counseled regarding further prevention of HIV transmission. Applying the national estimate to the number of people living with HIV/AIDS in Massachusetts reported to the HIV/AIDS Surveillance Program (N = 14,727 as of July 1, 2004), and adjusting for completeness of reporting, would yield an estimated 5,775 people who are infected with HIV and do not know it, and an additional 2,600 people who know their status but have not been reported. Therefore, the estimated total number of people currently living with HIV/AIDS in MA, including people known to the system as well as those yet to be identified, is in the range of 22,000 – 24,000 people.

People who are first diagnosed with HIV infection (that they may have been unaware of for a very long time) at the same time that they are diagnosed with AIDS are considered “concurrently diagnosed”. In the data that follow, a person is considered to have been concurrently diagnosed with HIV infection and AIDS if both the initial HIV infection and AIDS diagnosis occurred within two months. The profile of people who are concurrently diagnosed with HIV infection and AIDS highlights a population of people who may have first learned about their HIV infection status late in the progression of HIV disease. It is likely that people who are concurrently diagnosed with HIV and AIDS have been infected for more time prior to learning their HIV status than people who learn of their status before being diagnosed with AIDS. As such, the profile of people who are concurrently diagnosed with HIV infection and AIDS provides a good approximation of people who are infected but do not yet know. This group is one of the target populations for HIV counseling and testing efforts.

When using these data, one must keep in mind the confounding effects of place of birth. People born outside the US may have learned of their HIV status in their native country and then moved to Massachusetts (or elsewhere in the US) to receive care; as opposed to moving to Massachusetts, becoming infected with HIV and then learning about their HIV status late in the course of HIV disease. There is no way to differentiate between these two scenarios in the HIV surveillance data, although the latter represents a missed opportunity for Massachusetts care providers and the former may not. When

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<sup>1</sup> Fleming PL, Byers RH, Sweeney PA, Daniels D, Karon JM, Janssen RS. HIV prevalence in the United States, 2000. Abstract 11. 9<sup>th</sup> Conference on Retroviruses and Opportunistic Infections, Seattle, Washington, February 24-28, 2002

reviewing the proportion of concurrent diagnoses by race/ethnicity one should note the differences in the distribution of place of birth by race/ethnicity. Sixty-one percent of black individuals concurrently diagnosed with HIV infection and AIDS from 2001 to 2003 were non-US born compared to 34% of Hispanic individuals and 9% of white individuals.

**Table 6.1 People Diagnosed with HIV Infection and AIDS within Two Months and All People Diagnosed with HIV Infection by Gender, Race/Ethnicity, and Mode of Exposure: MA, 2001 – 2003**

	HIV and AIDS Diagnosed within 2 Months	All HIV Infection Diagnoses	% Diagnosed with HIV and AIDS within 2 Months
<b>Gender:</b>	<b>N</b>	<b>N</b>	<b>%</b>
Male	573	1,876	31%
Female	238	814	29%
<b>Race/Ethnicity:</b>	<b>N</b>	<b>N</b>	<b>%</b>
White (non-Hispanic)	302	1,085	28%
Black (non-Hispanic)	310	890	35%
Hispanic	180	627	29%
Asian/Pacific Islander	18	58	31%
Amer. Indian/Alaska Native	-- <sup>1</sup>	-- <sup>1</sup>	-- <sup>1</sup>
<b>Exposure Mode:</b>	<b>N</b>	<b>N</b>	<b>%</b>
Male-to-male sex (MSM)	213	867	25%
Injection Drug Use (IDU)	126	469	27%
MSM/IDU	13	62	21%
Heterosexual Sex	140	388	36%
Other <sup>2</sup>	6	8	75%
Total Undetermined	313	896	35%
• Pres. Heterosexual Sex <sup>3</sup>	235	636	37%
• Undetermined <sup>4</sup>	78	260	30%
<b>TOTAL<sup>5</sup></b>	<b>811</b>	<b>2,690</b>	<b>30%</b>

<sup>1</sup> Percentages calculated from a denominator and numerator of less than 5 are unstable and therefore not presented

<sup>2</sup> Other includes pediatric and blood/blood products

<sup>3</sup> Unknown risk of partner

<sup>4</sup> Includes those still being followed up for risk information, those who have died with no determined risk, and those lost to follow-up

<sup>5</sup> Totals include people of unspecified race/ethnicity

Data Source: MDPH HIV/AIDS Surveillance Program, Data as of 7/1/04

**Table 6.2 People Diagnosed with HIV Infection and AIDS within Two Months and All People Diagnosed with HIV Infection by Place of Birth and Age at HIV/AIDS Concurrent Diagnosis and HIV Diagnosis: MA, 2001-2003**

	HIV and AIDS Diagnosed within 2 Months	All HIV Infection Diagnoses	% Diagnosed with HIV and AIDS within 2 Months
Place of Birth:	N	N	%
US	443	1,655	27%
Puerto Rico and other US Dependencies <sup>1</sup>	72	262	27%
Non-US	296	773	38%
Age at Diagnosis:	N	N	%
0-12	-- <sup>2</sup>	-- <sup>2</sup>	-- <sup>2</sup>
13-19	6	42	14%
20-24	33	148	22%
25-29	73	302	24%
30-34	126	500	25%
35-39	169	597	28%
40-44	166	479	35%
45-49	112	326	34%
50+	123	293	42%
<b>TOTAL</b>	<b>811</b>	<b>2,690</b>	<b>30%</b>

<sup>1</sup> 94% of people diagnosed with HIV infection from 2001-2003 who were born in a US Dependency were born in Puerto Rico

<sup>2</sup> Percentages calculated from a denominator and numerator of less than 5 are unstable and therefore not presented  
Data Source: MDPH HIV/AIDS Surveillance Program, Data as of 7/1/04

<b>Table 6.3 People Diagnosed with HIV Infection and AIDS within Two Months and All People Diagnosed with HIV Infection by Gender and Race/Ethnicity: MA, 2001 – 2003</b>			
	<b>HIV and AIDS Diagnosed within 2 Months</b>	<b>All HIV Infection Diagnoses</b>	<b>% Diagnosed with HIV and AIDS within 2 Months</b>
<b>Males by Race/Ethnicity:</b>	<b>N</b>	<b>N</b>	<b>%</b>
White (non-Hispanic)	255	908	28%
Black (non-Hispanic)	176	480	37%
Hispanic	130	426	31%
Asian/Pacific Islander	11	42	26%
<b>Total Male<sup>1</sup></b>	<b>573</b>	<b>1,876</b>	<b>31%</b>
<b>Females by Race/Ethnicity:</b>	<b>N</b>	<b>N</b>	<b>%</b>
White (non-Hispanic)	47	177	27%
Black (non-Hispanic)	134	410	33%
Hispanic	50	201	25%
Asian/Pacific Islander	7	16	44%
<b>Total Female<sup>1</sup></b>	<b>238</b>	<b>814</b>	<b>29%</b>
<sup>1</sup> Totals include American Indian/Alaska Native and people of unspecified race/ethnicity Data Source: MDPH HIV/AIDS Surveillance Program, Data as of 7/1/04			